

The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders: informants, advocates or surrogate decision-makers?

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Background: This study examines the extent to which relatives of severely ill cancer patients are involved in the decision to limit treatment (DLT), their role in communicating patient wishes and the incidence of and reasons for disagreement with relatives.

Patients and methods: This cohort study followed 70 patients with terminal cancer, for whom a limitation of life-prolonging treatment was being considered. ‘Embedded researchers’ recorded patients’ wishes and the relatives’ roles and disagreements with DLT.

Results: Although 63 out of 70 patients had relatives present during their care, only 32% of relatives were involved in DLT. Physicians were more likely to know the end-of-life (EOL) preferences for those patients who had visiting relatives than those without them (78% versus 29%, $P = 0.014$). Most relatives supported patients in voicing their preferences (68%), but one-third acted against the known or presumed wishes of patients (32%). Disagreements with patients’ relatives occurred in 21% of cases, and predominantly when relatives held views that contradicted known patient preferences (71% versus 7%, $P = 0.001$).

Conclusion: If relatives are to play an important part in EOL decision making, we must devise strategies to recognise their potential as patients’ advocates as well as their own needs.

Key words: end-of-life decisions, ethics, family, relatives, treatment limitation

introduction

In the last few years, the role of families in end-of-life (EOL) care has gained increasing attention, driven by the necessity of surrogate decision making, especially in intensive care [1–3] where up to 90% of deaths are preceded by a decision to limit treatments (DLTs) [4]. Because <5% of patients are able to communicate with clinicians at that time, families often serve as informants regarding patient wishes [5]. There is a growing consensus regarding the importance of shared decision making in the intensive care unit (ICU), where clinicians and family members collaborate on decisions about life-sustaining treatments [6–8].

However, the role of relatives is less clear when the patient is still able to communicate but is very sick or on the verge of losing his or her decision-making capacity or when there is reason to believe that the relatives’ preferences differ from the

patient’s wishes. Should relatives be viewed only as informants about patient wishes or as advocates for patients’ preferences? Or, should relatives have a say in treatment decisions as ‘natural’ surrogates, even though they lack a legal mandate? In the case of disagreement, how can relatives’ own needs be reconciled with the patient’s preferences? So far, there are little empirical data about family involvement in DLT for non-ICU patients. Existing studies almost exclusively originate from ICUs and indeed they raise some concerns about family involvement. Involved relatives showed a higher rate of posttraumatic stress symptoms [9], many relatives experienced disagreement with the health care team [10] and clinicians have questioned whether relatives express authentic patient wishes. To our knowledge, however, there are no data that document the actual role of family members or the incidence and reasons for disagreement about DLT in patients who are not incapacitated at the time of decision making.

In this study, we took an on-site approach by utilising ‘embedded researchers’ on the wards [11], combining observation of family involvement on daily rounds with interviews with clinicians, patients and family members.

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We present results describing (i) the role of family members in DLT, (ii) factors affecting family involvement and (iii) the frequency and reasons for disagreement between clinicians, patients and family in DLT.

methods

A prospective cohort study design was chosen including patients who were admitted within a 15-month period to the Department of Haematology and Oncology at the University of Munich Medical Centre. Patients older than 18 years were eligible if the question of forgoing or terminating treatment options was being discussed. The decision-making process regarding limiting treatment (DLT) was observed until the death of the patient or the discharge to home or hospice. Either the patient or the legal substitute decision-maker gave informed consent to participation in the study, which was approved by the independent ethics committee of the institution.

data collection

In order to document the process of DLT as realistically as possible, a structured documentation form (7 categories, 54 questions) was completed by two embedded researchers trained to gather information in a standardised manner [12]. It was based on chart review, structured enquiry of physicians and patients and systematic follow-up on the decision-making process on a daily basis until death or discharge of the patient. We reported patient recruitment, data prioritisation and integration for patient involvement in DLT before [12]. With regard to the role of relatives in DLT, the following information was recorded:

- (1) The availability of relatives defined as patients with visiting relatives.
- (2) The role and involvement of family member in DLT as indicated by physicians, patients or relatives and verified by the embedded researchers' observation.
- (3) The incidence and reasons for disagreement with relatives.
- (4) Family members' influence of decision outcomes, especially in cases of disagreement.

We defined a minimal standard for family involvement in the discussion about DLT, which required that family members participate in the discussion about EOL- care with the physician and that they be notified when the physicians actually decided to limit treatment. To further determine the relatives' role in EOL- care, we observed what stance they took on the patient's EOL- care and whether their agenda differed from the patient's known or assumed preferences. This information was supplemented by the embedded researchers' documentation of the family's interaction with the patient during the interview and follow-up visits. Finally, the relatives' roles in communicating patient preferences were stratified into three groups by an independent researcher: group 1), patients whose relatives helped to make their preferences heard; group 2, patients whose relatives' agenda differed from known patient preferences; group 3, patients who were unable to communicate, and whose providers questioned whether family members' wishes represented the authentic patient wishes.

Group 1 was summarised as family members supporting patient preferences; groups 2 and 3 were combined in the category 'family members not supporting patient wishes'. These data were aligned with the following information about the decision-making process from the patient and physician perspective: Patient ability to communicate, patient wishes for EOL- care and patient involvement in DLT

- (5) Physicians' knowledge of the patient's EOL preferences and perceived disagreement in DLT. The influence of relatives on decision outcomes was analysed in cases where the family members' views about the right course of action differed from either the patient's or clinician's view (disagreement cases). If their view prevailed in the final decision, we

concluded that family members had a strong influence on decision outcomes.

Content validity was evaluated by consensus of an expert panel and reviews of the literature. The documentation form was pretested in haematology–oncology and had been used in a parallel collaborative study on DLT in neonatology [13]; the form was further developed in a smaller in-depth case series on DLT in intensive care [14]. All items of the documentation form were encoded using the same coding conventions by two researchers.

statistical methods

Descriptive statistical analysis was carried out on patient characteristics, their preferences for EOL- care, information about family members and details about the decision process. To test whether differences in family involvement or the role of relatives were associated with patient characteristics, the Mann–Whitney test was used for numerical data and χ^2 test or Fisher's exact test in cross tabulations. Two-tailed *P* values <0.05 were considered statistically significant. Multiple logistic regression analysis was done to assess the strength and independence of effects of patient characteristics, disagreements and role on involvement of relatives in DLT. Data analysis was carried out using SPSS/Win, version 14.0 (SPSS Inc, Chicago, IL).

See supplementary material (available in *Annals of Oncology* online) for more details on the method of patient recruitment, data acquisition and work up.

results

characteristics of patients with and without visiting relatives

A majority of patients (63 out of 70) had relatives who were present in patient care. Table 1 compares characteristics of patients with and without available relatives. The two groups showed a gender difference with all patients without relatives being male (*P* = 0.016). While the presence of family members had no significant influence on patient involvement in DLT, physicians knew significantly more often about patient preferences in patients with visiting relatives (78% versus 29%, *P* = 0.014) (Table 1).

role of family members communicating the patient's wishes

The number of relatives sharing in patient care varied between one and seven (median 1), with the spouse (59%) or children (21%) being the primary contact person in most patients (Table 2). Thirty patients were supported by their family members in making their preferences heard (68%); in eight patients (18%), relatives acted against the known wishes of the patient, and in six patients (14%) who were unable to communicate, clinicians thought relatives did not represent authentic patient wishes. Five patients did not allow their relatives to play an active role in decision making. They were excluded from this analysis.

involvement of family members in DLT

Data about family involvement were available in 60 out of 63 patients with visiting relatives (Table 3). Relatives were 'involved' in the discussion about limiting treatment in only 19 (32%) and 'informed' about DLT in 35 patients (58%). Family members of six patients were not included in the conversation

Table 1. Comparative characteristics of patients with and without involved relatives; significant differences between the groups are highlighted by bold *P*-values

No. of patients in subgroups	All patients (<i>n</i> = 70)	Patients with relatives (<i>n</i> = 63)	Patients without relatives (<i>n</i> = 7)	<i>P</i>
Age, median (range)	60 (30–82)	60 (30–82)	56 (50–69)	0.88
Karnofsky performance scale, median (range)	50 (10–90)	50 (10–90)	50 (30–90)	0.44
Sex, No. (%)				0.016
Female	30 (43)	30 (48)	0 (0)	
Male	40 (57)	33 (52)	7 (100)	
Patient preferences known to medical team, No. (%)				0.014
Yes	51 (73)	49 (78)	2 (29)	
Patient prefers quality of life	36	35 (71)	1	
Patient prefers length of life	15	14 (29)	1	
No	19 (27)	14 (22)	5 (71)	
Patient involvement, No. (%)				0.24
Involved in DLT	34 (49)	32 (51)	2 (29)	
Not involved	36 (51)	31 (49)	5 (71)	
Patient coping, No. (%)				0.19
Realistic	27 (39)	26 (41)	1 (14)	
Denial	16 (22)	14 (22)	2 (29)	
Missing data	27 (39)	23 (37)	4 (57)	
Ability to communicate, No. (%)				0.75
Possible	38 (54)	34 (54)	4 (57)	
Reduced due to primary cognitive limitations	21 (30)	19 (30)	2 (28)	
Reduced due to cognitive deterioration	7 (10)	7 (11)	0 (0)	
Reduced due to language barrier	4 (6)	3 (4)	1 (14)	

about DLT: in three patients, this was because the patients themselves had been not informed about DLT, in one case, the patient did not want the relatives to be involved, and in two cases, no information was available on why the family did not participate. One would expect that a patient's inability to communicate would serve as a good predictor for family involvement because relatives could serve as advocates for incapacitated patients (Table 3, first column). Surprisingly, relatives of patients with limited ability to communicate were not involved more often in DLT than relatives of patients who could speak for themselves. Relatives' involvement in DLT did also not change significantly over the time of the disease. Actually, the main predictor for the involvement of relatives was the involvement of the patient himself or herself: 15 involved patients had their relatives involved in DLT (47%) as compared with only 4 patients (14%) who had not been involved in DLT themselves ($P = 0.001$). Whether patients opted for quality or length of life was associated with their coping strategy: 23 of 26 patients with realistic coping strategies preferred treatment focusing on quality of life, whereas only 3 of 12 patients in denial did so (88% versus 25%, $P = 0.005$). As a consequence, relatives of patients in denial were involved less often than relatives of patients with an appropriate perception of their situation (7% versus 50%, $P = 0.013$) (Table 2, first column). The data about the coping behaviour of patients with active family members were covered by four sources of information in 4 patients, by three sources in 9 patients, by two sources in 13 patients and one source in 15 patients.

Binary logistic regression analysis of the association between involvement of family members and patient age, Karnofsky

performance index, ability to communicate and disagreement with relatives showed no significant influence on any parameter (data not shown).

incidence and reasons for disagreement with relatives and relatives impact on decision outcomes

Disagreement in the interaction with relatives was observed in 13 out of 63 patients (21%). It occurred more often in patients whose relatives did not support patient wishes as compared with patients whose relatives did (71% versus 7%, $P = 0.001$) (Table 3, second column). We observed a weak tendency of more disagreements occurring with relatives as the disease duration of the disease extends ($P = 0.645$): disagreements occurred in 15% of patients with <1 year of disease duration, in 18% of patients with 1–2 years of disease duration and in 27% of patients being diagnosed >3years ago ($P = 0.64$). Disagreement occurred within the families of seven patients (54%), between the physician and the family/patient in four patients and between the family and the physician/patient in two cases (Table 4). The most frequent source of disagreements regarded treatment goals (eight patients/61%). Four patients wished to be discharged to home, but family preferred them to stay hospitalised. Family members did influence treatment outcomes in 7 out of 13 disagreement cases (54%). Their influence on the final decision was strongest regarding discharge and hospitalisation; all four disagreements were resolved the way the relatives preferred. In disagreements about DLT, the relatives' views prevailed in the final decision in two out of eight cases (Table 4).

Table 2. Characteristics of family members [No. (%)] and frequency of decisions to limit life-prolonging treatment

	No. (%)
Patients with relatives	
Present	63 (90)
Not present	4 (6)
Nonexistent	3 (4)
Number of relatives sharing in patient care	
No relatives	7 (10)
One relative	35 (50)
Two relatives	16 (23)
Three relatives	8 (11)
More than three relatives	4 (6)
Primary contact persons within the family	
Spouse	37 (59)
Children	13 (21)
Siblings	1 (2)
Others	3 (5)
No data	9 (14)
Role of relatives in communicating the patient's wishes for EOL care	<i>n</i> = 44
Actively supporting	30 (68)
Acting against patient wishes	8 (18)
Impeached surrogacy	6 (14)
Decisions to limit life-prolonging treatment included	
No resuscitation	56 (80)
No transfer to ICU	42 (60)
No chemotherapy	13 (18)
No radiation	2 (3)
No surgery	3 (4)
No antibiotics	3 (4)
No bone marrow transplantation	2 (3)

EOL, end-of-life care; ICU, intensive care unit.

discussion

In this prospective cohort study, we described the roles that relatives play in DLT in patients with end-stage malignant disorders. The key findings about the caregivers' roles in EOL decision making were that (i) two-thirds of relatives acted as advocates for their patient's preferences, but only one-third were actually involved in DLT. (ii) Also, relatives of patients who were unable to communicate were involved less often as 'natural' surrogates than a shared decision-making approach to DLT would suggest. (iii) Disagreement with family members occurred with one out of every five patients, chiefly when relatives held views that differed from known patient preferences. Such views differed in about one-third of patients and this is probably a major source of distress for family, patients and providers [15].

the roles of patient relatives: advocates or 'natural' surrogates in DLT?

Relatives were actively involved in DLT in one-third of the cases. This falls well within the proportion of family involvement that has been reported for the intensive care setting, a measure that

varies from 17% to 44% in European countries [16, 17].

Contrary to our expectation that relatives would function as 'natural' surrogates, family members of patients who could not speak for themselves were not involved more frequently. This is striking in the light of studies suggesting that most patients want their families to act as representatives if they become incapacitated. Our data show that actually two-thirds of relatives did support their patients in voicing their preferences and acted as their advocates in DLT [18, 19].

Three reasons may explain the low frequency of family members' involvement. First, in the majority of cases, there was no need for relatives to advocate patient preferences since all participants agreed on comfort care. Second, non-involvement of family members may have resulted from the physicians' strict interpretation of the legal requirements for patients without formal surrogate designation. Unauthorised family members of incompetent adult patients may, according to German and most (Central) European legislations, only serve as informants of the presumed wishes of their patient [2, 3]. Third, relatives of patients in denial were significantly less often involved in DLT than those of patients with realistic coping behaviour. It has been shown before that most of the patients in denial did not agree with the palliative care recommendations of their physicians and had not been involved in the actual DLT [12].

are family members authentic advocates for patient preferences?

Two-thirds of patients were supported by their relatives in making their wishes heard; in one-third, relatives held different views about the right course of action. The incidence of disagreement between family members and clinicians was high when relatives held (i) a view that differed from the known patient wishes or (ii) a view that was challenged by clinicians as not representing the patient's authentic wishes.

While for the former group (i) it is documented that relatives followed their own preferences, we do not have information on the latter group (ii) to substantiate the physicians' doubts. Clinicians' doubts that family members acted as appropriate patient representatives have been reported across a broad range of cultures in North America and Europe [20]. In a study in French ICUs, half of those intensive care specialists who were unwilling to involve family members gave as their main reason a tendency of families to express their own wishes rather than those of the patient [21]. In our study, this concern is warranted in one-third of patients, whereas family members did act as authentic advocates for the patient in two-thirds of cases. There are controversial data on how accurate family members and physicians are at predicting patient preferences, suggesting that neither are more accurate than a coin toss [22–24].

incidence and reasons for disagreement with relatives and their influence on decision outcomes

Disagreement with family members during DLT was observed in 21% of patients. The number of disagreements reported in the literature varies widely from 10% [25] to as high as 78% [26] of patients in whom EOL decisions had to be made. This variation may in part be explained by the likelihood of perceived disagreements increasing with the number of persons

Table 3. Comparison of characteristics of patients whose relatives were involved in decisions to limit treatment and whose relatives were not involved (pale grey shaded columns), and of patients whose relatives supported their preferences for end-of-life care and those whose relatives pursuit goals that differed from patient goals (darker grey shaded columns); significant differences between the groups are highlighted by bold *P*-values

No. of patients in subgroups	Relatives involved (<i>n</i> = 19)	Relatives not involved (<i>n</i> = 41)	<i>P</i>	Relatives supporting patient wishes (<i>n</i> = 30) ^a	Relatives not supporting patient wishes (<i>n</i> = 14) ^a	<i>P</i>
Age, median (range)	60 (30–82)	60 (33–77)	0.85	59.5 (30–82)	61 (32–76)	0.62
Karnofsky performance scale, median (range)	40 (10–90)	50 (10–90)	0.34	45 (10–90)	50 (20–90)	0.65
Communication, No. (%)			0.51			0.81
Possible	11 (35)	20 (65)		14 (70)	6 (30)	
Limited/not possible	8 (28)	21 (72)		16 (67)	8 (33)	
Disease duration ^b , No. (%)			0.24			0.84
<1 year (versus 1–3 years)	6 (23)	20 (77)	0.20	13 (68)	6 (32)	0.59
1–3 years (versus 3 years)	7 (41)	10 (59)	0.12	10 (77)	3 (23)	0.59
>3 years (versus <1 year)	2 (15)	11 (85)	0.58	6 (67)	3 (33)	0.93
Patient involvement, No. (%)			0.001			0.98
Involved in DLT	15 (47)	17 (53)		17 (56)	8 (57)	
Not involved	4 (14)	24 (86)		13 (44)	6 (43)	
Disagreement with relatives, No. (%)			0.55			0.001
No	14 (74)	33 (80)		28 (93)	4 (29)	
Yes	5 (26)	8 (20)		2 (7)	10 (71)	
Patient preference for EOL care, No. (%)			0.39			0.102
Quality of life	13 (76)	20 (65)		20 (83)	7 (58)	
Length of life	4 (24)	11 (35)		4 (17)	5 (42)	
Missing data	2	10		6	2	
Patient coping, No. (%)			0.013			0.53
Realistic	13 (93)	13 (50)		14 (77)	6 (66)	
Denial	1 (7)	13 (50)		4 (23)	3 (34)	
Missing data	5	15		12	5	
Physician patient disagreement about DLT, No. (%)			0.32			0.05
No	14 (87)	23 (77)		21 (95)	9 (69)	
Yes	2 (13)	7 (23)		1 (5)	4 (31)	
No data on patient preferences	3	11		8	1	

^aSecond column includes only patients whose relative's role was known: relatives either supported the patient's wishes or acted against them (*n* = 44).

^bAll three groups were tested against each other.
EOL-care, end-of-life care.

interviewed. In one of the few studies that focused on disagreement in EOL decision making, the incidence of disagreement between family and staff (33%) was similar to our proportion of 31% of disagreement between physician and family in alliance with the patient [26].

Disagreements about DLT have gained much attention in the literature and were the most common cause of conflict in this study [15], with six out of eight disagreements arising because relatives preferred a more aggressive treatment than the patient and the physicians. This resonates with studies that report relatives find DLT more difficult than does the patient [27]. We also found that discharge to home or to hospice caused disagreement in a significant number of cases; these issues might be specific to severely ill patients in the non-ICU setting. While physicians were responsive to the relatives' preferences concerning discharge to home or hospice in all disagreement

cases, they gave precedence to the patients' preferences in most disagreements about DLT (Table 4).

This study has several limitations. While we did not ask relatives directly about their preferred role in decision making, we know from previous studies that most relatives prefer an active role in decision-making, but only 15%–30% who prefer to leave decisions with the physician [6, 21]. It seems very likely that relatives would have wished to participate in DLT in more than the observed one-third of patients.

We did not ask the physicians how they conceptualise the role of relatives in DLT and why they did not involve some family members. Physicians may have wanted to protect family members from burdensome involvement [9]. Furthermore, studies show that shared decision making in EOL decisions is often incomplete with the family's role being the least frequently discussed element [7, 12].

Table 4. Overview of all conflict cases with description of patient preferences, physician's treatment goals and preferences of family members as well as their influence on decision outcomes

No.	Patient preference	Physician's recommendation	Disagreeing parties	Description of disagreement	Patient's ability to communicate	Relatives supporting patient wishes	Final decision	Influence on final decision
Disagreement about treatment goals								
1	Comfort care	Comfort care	Patient/physician-relative	Patients' husband asks for active treatment	Given	No	Comfort care	No
2	Comfort care	Comfort care	Patient/physician-relative	Patients' son insists on active treatment	Given	No	Comfort care	No
3	Comfort care	Comfort care	Disagreement between relatives	Patients' daughter supports patient wish, but all other relatives want the patient to transfer to another hospital for active treatment	Limited	Contested surrogacy	Comfort care	No
4	Comfort care	Comfort care	Patient-relatives	Spouse insists on active treatment. Patient does not protest	Limited	No	Active treatment	Yes
5	Active treatment	Comfort care	Patient/relatives-physician	Relatives prefer active treatment in the beginning, but after conversation with the physicians they preferred comfort care	Given	No	Comfort care	Probably no
6	Active treatment then comfort care	Comfort care	Physician-relatives	Patient changes his mind as his condition deteriorates. Patients' son insists on active treatment	Limited	No	Comfort care	No
7	Active treatment	Comfort care	Patient-relative	Husband does not want to extend the suffering of his wife, votes for comfort care	Limited	Contested surrogacy	Comfort care	Probably no
8	Comfort care then active treatment	Comfort care	Physician-relatives	Patient was persuaded by family members to take the risk of an operation with questionable benefit	Limited	No	Operation (no DLT)	Yes
Disagreement about discharge to home or disclosure								
9	Discharge to daughter's home	Discharge to home	Disagreement between relatives	Daughter supports patient wish. Husband wants the patient to stay in the hospital or be transferred to Turkey to other relatives	Limited	Yes	Discharge to daughters home	Yes
10	No preference known	Discharge to hospice	Physician-relative	Patient's wife wants the patient to stay in the hospital because the patient is so weak. Patient stayed and died a few days later	Limited	Yes	No discharge	Yes

Table 4. (Continued)

No.	Patient preference	Physician's recommendation	Disagreeing parties	Description of disagreement	Patient's ability to communicate	Relatives supporting patient wishes	Final decision	Influence on final decision
11	Discharge to home	Discharge to home	Patient-relative	Patient's wife and daughter prefer transfer to a nursing home	Given	No	Discharge to nursing home	Yes
12	Discharge to home	Discharge to home	Patient-relative	Relatives organise to transfer patient to a nursing home without informing the patient about their plans	Given	No	Discharge to nursing home	Yes
13	No disclosure to spouse	Neutral position	Patient-relative	Patient does not want his spouse to know about his disease, she insists to be involved	Limited	Not allowed to support	No disclosure spouse	Yes

conclusions

Our data suggest that the clinical practice for non-ICU cancer patients does not encourage family members routinely to participate in DLT. Physicians should utilise the full potential of relatives as advocates for patient preferences, especially in incapacitated patients who may benefit from the voices of relatives. However, if relatives are allowed to weigh in on EOL decisions, physicians need to ascertain that these relatives express authentic patient wishes. Therefore, physicians first need to learn whether patients want their relatives to participate in DLT and about the patients' preferences and their relatives' needs. Our study shows that patients in denial, as well as their relatives require particular attention and support from clinicians to enhance appropriate coping and to share decision making. Just as we needed studies and training to learn how to involve patients appropriately in EOL decisions [28], we now need strategies to ensure family participation that is in the best interest of both patients and relatives.

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